

What you need to know about **Hepatitis C**



Did you know that in the United States, almost 3 million people have hepatitis C?

If you are one of them, you probably have many questions. This booklet can help you learn about symptoms, treatment, substance use, staying healthy, and more.

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Hepatitis C: The Basics

What is hepatitis C?

“Hepatitis” means “liver disease.” Hepatitis C is a kind of liver disease caused by the Hepatitis C Virus (HCV).

Up to 85% of people who are exposed to HCV develop long-term (chronic) hepatitis C infection. Long-term hepatitis C infection can lead to liver scarring (cirrhosis), liver disease, or liver cancer.

Other kinds of hepatitis can be caused by other viruses, by alcohol, or by medication. A person can have more than one kind of hepatitis at the same time.

What are the symptoms of hepatitis C?

Most people with hepatitis C have no symptoms for many years. Some never have symptoms at all. But some people have symptoms like:

- feeling very tired
- fever
- yellowish skin and/or eyes
- dark urine
- upset stomach
- light-colored stools
- stomach pain

The only way to know if you have hepatitis C is to have a blood test.
How do people get hepatitis C?

Hepatitis C is passed from one person to another through infected blood. For example:

- ☐ sharing syringes and injection equipment (works)
- ☐ needle-stick injuries, usually to health care workers on the job
- ☐ from mother to baby during birth
- ☐ sex without using a condom



See pages 7 and 8 to learn more about how hepatitis C is passed from one person to another..

What will hepatitis C do to my health?

Five to 15% of people with hepatitis C will get severe liver damage and scarring (cirrhosis) of the liver or liver cancer. This often happens slowly, over many years. Some people have no problems for 20 or more years after infection. Others become sick much sooner.

Severe liver damage can lead to:

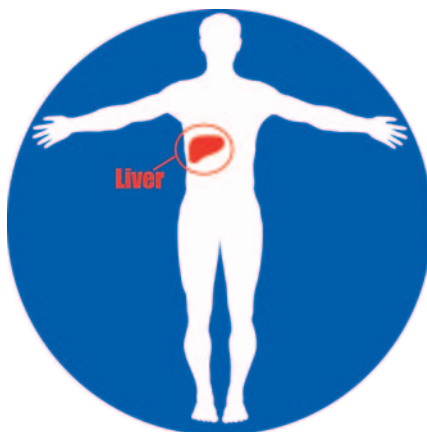
- ☐ problems with blood clotting
- ☐ swelling of the stomach and ankles
- ☐ not being able to think clearly
- ☐ liver failure
- ☐ needing a liver transplant

It can be scary to find out about the health problems that hepatitis C can cause. Remember that many people with hepatitis C stay healthy for years. Not everyone with hepatitis C will have serious liver problems.

What does my liver do, anyway?

Your liver is one of the most important organs in your body. You can not live without it. Some of its jobs are:

- ❑ processing some medicines
- ❑ filtering poisons out of your blood
- ❑ helping to fight infection
- ❑ changing food into substances your body needs
- ❑ making substances that help your blood clot
- ❑ storing vitamins and energy



Many people with hepatitis C also have HIV.

HIV is the virus that causes AIDS. Like hepatitis C, HIV is spread through contact with infected blood. HIV is also spread during unprotected sex.

If you have ever shared needles or had vaginal, anal, or oral sex without a condom, think about getting an HIV test. If you test positive, there are treatments that can help you stay healthier. To get more information and find out where you can get a free HIV test without giving your name, call: 1-800-541-AIDS /1-800-233-SIDA (Spanish).

If you have HIV, your hepatitis C may get worse faster. Most people can be treated for HIV and hepatitis C at the same time.

Tracking Hepatitis C in Your Body: Blood Tests & Biopsies

Some people with hepatitis C get severe liver damage. Others never get very sick. Most people do not have any symptoms until they have serious problems. So how can you find out what hepatitis C is doing to your liver?

Blood tests are one way to find out how hepatitis C is affecting your body. There are two kinds of blood tests your doctor may do:

- ❑ **Liver function tests** measure substances in your blood to look for warning signs of liver damage. But hepatitis C can be tricky. A blood test may be normal even though your liver is being damaged. Or, a blood test may not be normal even though your liver is healthy. Liver function tests are most useful when done on a regular basis (once or twice a year) to look for long-term patterns in how your liver works.
- ❑ **A viral load test** measures the amount of hepatitis C virus in your body. A viral load test is usually done once when you are diagnosed and once or twice when making treatment decisions. If you decide to get treated for hepatitis C, your doctor will use viral load tests to see how well the treatment is working.

Blood tests are helpful, but they don't tell the whole story. To get a better idea of how hepatitis C is affecting you, your doctor may want to look at your liver directly by doing a liver biopsy.

In a liver biopsy, the doctor uses a long, thin needle to remove some tissue from your liver. The doctor will look closely at



the liver tissue to see if it is damaged. This is the most exact way to find out what hepatitis C has done to your liver. Not everybody needs to have a liver biopsy, but it may be helpful if you are thinking about treatment.

A liver biopsy is usually not very painful. You do not need to be “knocked out.” Instead, the doctor will numb your stomach area before the biopsy. Very rarely, a person may bleed or have severe pain after a biopsy. Although this does not happen often, the doctor will want you to stay at the hospital for a few hours after your biopsy—even if you feel fine—to make sure there are no problems.

Wanda:

“I need to stay healthy, because I have two little girls and they keep me busy! I had a biopsy and my doctor says my liver is doing okay. So far, so good...”

“...but I worry about my family. Sometimes I let my kids drink from my glass, or I forget to cover my mouth when I cough. Could that give them hepatitis C? And what about my partner? Can you get hepatitis C through sex?”



Hepatitis C is **not** spread through casual contact like coughing, sharing cups or eating utensils, hugging, or kissing. Hepatitis C is only spread through **contact with infected blood**. The most common ways that hepatitis C is spread are:

- ❑ sharing needles and other equipment (“works”) used to inject drugs or other substances
- ❑ mother to baby during birth
- ❑ accidental needle-stick injuries, mainly to health care workers on the job
- ❑ sex without using a condom (this is a rare way to get hepatitis C, but it does happen)

It may also be possible to spread hepatitis C through:

- ❑ sharing razors, toothbrushes, or nail clippers with a person who has hepatitis C (because these items may have traces of blood on them)
- ❑ tattoos or piercing, especially if it is not done by a professional with sterile equipment

A woman can pass hepatitis C to her baby during birth. About 5 out of 100 babies born to women with hepatitis C will be infected. Talk to your child's doctor about when to test your child for hepatitis C.

Before 1992, people also got hepatitis C through infected blood transfusions and organ transplants. Now, all blood and organ donations are tested for hepatitis C, so it is safe to get blood or organs.

It is possible to spread hepatitis C during sex, but this is rare. On the other hand, HIV and other STDs (sexually transmitted diseases) are easily spread during sex. Always use condoms to protect yourself and your partners.

Keeping your loved ones safe

Hepatitis C is spread through blood. To avoid giving hepatitis C to others:

- ❑ do not share needles, syringes, or other injection equipment ("works")
- ❑ do not share razors, toothbrushes, nail clippers, or other household items that could have blood on them
- ❑ clean up blood spills right away with bleach
- ❑ keep cuts or sores covered with a bandage



Carlos:

“When I found out that I had hepatitis C, I was really angry. I worked so hard to get off drugs and was just starting to get my life together. Then they told me I had this disease. I couldn’t believe it. I didn’t go back to the doctor for a while—I didn’t want to deal with it.

Later I realized it wasn’t going to just go away. I want to stay as healthy as I can. Is there is a treatment for hepatitis C?”

You are not alone. Dealing with recovery and hepatitis C can be stressful. It may help to know that there are many other people in the same situation. Ask your doctor, counselor, or case manager about support groups for people in recovery who have hepatitis C.

There is a treatment for hepatitis C, but it does not work for everybody. The treatment is a combination of two medicines: **pegylated interferon** and **ribavirin**. Pegylated interferon is injected under the skin (like a shot) once a week. Ribavirin is a pill that you swallow. Treatment usually lasts for 12 months; sometimes it is shorter.

Hepatitis C treatment does not work for everyone:

- ❑ About half of people treated with pegylated interferon and ribavirin have healthier livers and no hepatitis C in their bodies at the end of treatment.
- ❑ Some people's livers get healthier during treatment, but the hepatitis C is not completely removed from their bodies. They may still have liver damage from hepatitis C in the future.

“I’m also in a methadone program. Will I have to stop taking methadone if I want treatment for hepatitis C?”

No. You can be treated for hepatitis C while you are on methadone.



Michael:

“My doctor says I should think about getting pegylated interferon and ribavirin treatment for my hep C. She says it has a good chance of helping my liver.

But I’ve heard that interferon has side effects that really mess you up. I have HIV, and when I started taking HIV medicines, I felt

sick all day long. My doctor changed my HIV treatment, and I feel okay now, but I don’t know if I want to deal with side effects like that again.



What are the side effects of hepatitis C treatment?
Do most people get them?”

Pegylated interferon and ribavirin are strong drugs. Many people treated with them get side effects like:

- ❑ flu-like symptoms (fever, chills, headache, muscle pain)
- ❑ feeling very tired (fatigue)
- ❑ mood changes (depression, bad temper)
- ❑ temporary hair loss
- ❑ anemia (reduced red blood cells)

Some people have mild or no side effects. Some people have very severe side effects. For many people, the side effects become less severe over time.

“I don’t know if I’m ready for all that. Do I have to start treatment for hepatitis C right away?”

This is not an easy question. There are good reasons to delay treatment—and good reasons to start treatment sooner:

Reasons to delay hepatitis C treatment	Reasons to start hepatitis C treatment sooner
<ul style="list-style-type: none">❑ Side effects from interferon and ribavirin could make you sick.❑ Better treatments may be available in the future.❑ Your hepatitis might not get worse—some people never have serious liver problems.	<ul style="list-style-type: none">❑ Treatment might not work as well later.❑ Your hepatitis C could get worse very fast.❑ If your liver gets too badly damaged, you might need a liver transplant.

When and how to treat your hepatitis C is a hard decision. Family needs, side effects, work, substance use, health issues, and many other parts of your life will affect your choice. Your doctor or nurse can help you look at all of the factors to decide what is best for you.

Depression is a common side effect



Severe depression can happen to anyone who is taking interferon. It is more likely in people who have a history of depression or other mental illness. If you have a history of any mental illness or substance use/abuse, tell your doctor before you

begin treatment with any type of interferon. Your doctor may suggest that you start anti-depressant medicine or see a psychiatrist before you begin your hepatitis C treatment. Your doctor can also refer you to support services like hotlines or counseling so that if you do have mood changes, you can get help right away.

If You Use Drugs, Here's What You Need to Know

The healthiest choice is to stop using. Drug use is linked to many health problems, and you need to keep your body as healthy as possible. Also, you don't always know what you are getting when you buy street drugs. They may be cut with substances that can hurt your liver. If you can't quit, reduce your drug use as much as you can.

Injecting drugs puts you at risk for hepatitis C, HIV, and other infections. If you are going to inject drugs, do it as safely as you can:

1) Use a new needle and syringe every time.

In New York State, through ESAP (Expanded Syringe Access Demonstration Program), you can buy up to 10 new, clean syringes at many drugstores. You do not need a prescription. You can also trade used syringes for new syringes at a syringe exchange program. To find a syringe exchange program or a drugstore that sells syringes without a prescription, call:

1-800-541-AIDS (English)

1-800-233-SIDA (Spanish)

1-800-369-AIDS (Deaf/TDD)

2) Don't share needles or works — including cookers (spoons, bottlecaps), cotton, ties, and water.

You might think that if you don't share needles and syringes, you are not at risk. But you can also get hepatitis C, HIV, and other infections from tiny traces of blood in water, cotton, cookers (spoons, bottlecaps, etc.), or anything else you share when you shoot up.



- 3) If you have to re-use a needle and syringe, first clean it with bleach and water.

These steps may help reduce your hepatitis C risk, but injecting drugs is never safe. To clean a needle and syringe:

- ❑ Wash your hands and try to clean your works in a space that is separate from others.
- ❑ Fill the syringe half full with clean water; pull back on the plunger. Shake the syringe and squirt the water through the needle. Repeat 2 times with new water, or until all the blood is gone.
- ❑ Fill the syringe with full strength bleach. Shake. Squirt the bleach out through the needle. Repeat.
- ❑ Rinse the syringe 3 more times with clean water.
- ❑ Do not re-use water or bleach. Be sure to keep the rinse water apart from water used to prepare drugs.



Hepatitis C treatment for drug users

If you use drugs, you can still be treated for hepatitis C. However, you should think about whether your drug use will cause problems in your treatment, like missing doctor's appointments or doses of medicine. Your doctor, counselor, or case manager can help you decide whether hepatitis C treatment is a good option for you right now.

Alcohol & the liver

Alcohol is very hard on your liver. If you have hepatitis C, alcohol could make your hepatitis get worse, and get worse faster. If you drink while in treatment for hepatitis C, the treatment may not work as well for you. The less you drink, the better. Quit if you can.

Staying Healthy: Your choices make a difference!

Even if you have hepatitis C, there are many things you can do on your own to keep your liver healthy:

✓ **Get hepatitis A and hepatitis B vaccines.**

Hepatitis A and hepatitis B are liver diseases similar to hepatitis C. Hepatitis A, especially, can be very serious in someone with hepatitis C. Protect yourself! Most doctors and clinics have these vaccines.

✓ **Avoid alcohol.**

Alcohol hurts your liver and will probably make your hepatitis C worse. The less alcohol you drink, the better. The healthiest choice is not to drink any alcohol at all.

✓ **Tell your doctor about every medication or drug that you are taking. This includes:**

- ❑ prescription medications
- ❑ herbal pills or extracts
- ❑ over-the-counter medications like headache pills or cold medicine
- ❑ street drugs

One of your liver's jobs is to process medications. Your doctor needs to know everything that you take in order to help your liver work and keep you healthy.

Telephone Hotlines:

For more information about hepatitis C, call toll-free:

1-888-4-HEP-CDC **CDC Hepatitis Hotline**
(1-888-443-7232)

For help quitting or reducing your alcohol and drug use, call:

1-800-522-5353 **New York State Office of Alcohol &
Substance Abuse Services (OASAS)**
Monday – Friday, 9 a.m. – 5 p.m.

1-800-LIFENET **New York City only**
(1-800-543-3638) 24 hours a day, 7 days a week

1-800-LIFENET also offers confidential help with depression and other mental health problems.

To find syringe exchange programs, pharmacies that sell syringes without a prescription, HIV test sites, and information about HIV and AIDS, call the toll-free New York State Department of Health HIV/AIDS Hotline:

1-800-541-AIDS **English**

1-800-233-SIDA **Spanish**

1-800-369-AIDS **Deaf/TDD**

You can listen to taped messages or speak to a phone counselor. You can ask them anything, and you do not need to give your name.



Internet Resources:

There are many health resources on the Internet. If you do not have access to a computer, try your local library. Most libraries have internet access that you can use free of charge, and they can show you what to do if you need help. Librarians are not required to keep information private, but you don't need to tell them what information you are looking for or which websites you plan to view. Try these websites:

www.health.state.ny.us

www.cdc.gov

www.hivandhepatitis.com

www.niddk.nih.gov/index.htm

www.hepfi.org

Notes:
